

Renewal and Rediscovery: Insights from Memoirs of Illness and Disability



BY RAY D. KENT



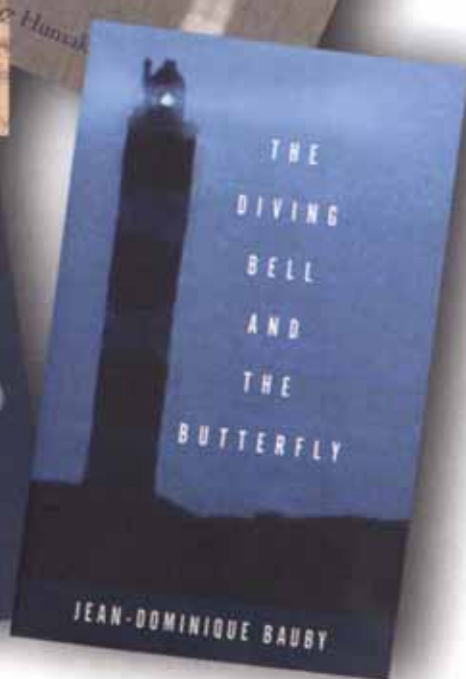
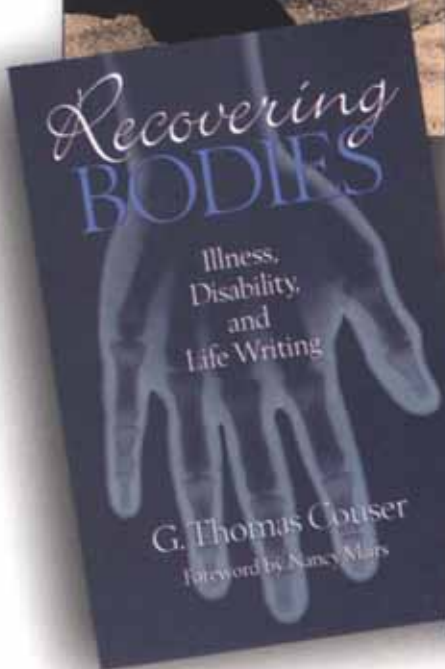
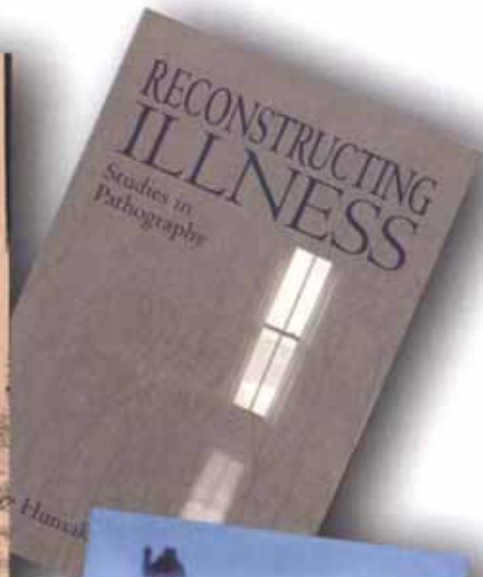
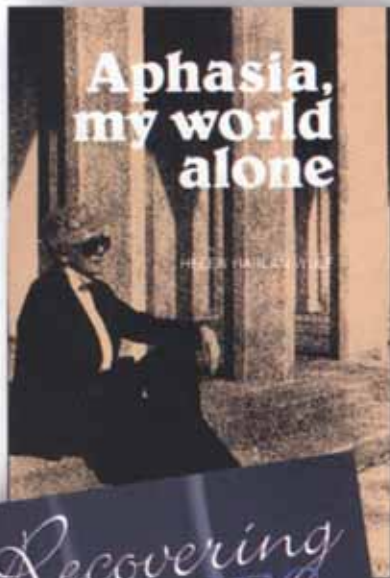
A relatively new literary genre, known by names such as pathography, illness narratives, or disability memoirs, are accounts of living with, and sometimes dying from, an illness or disability. They are written by patients, their caregivers, and occasionally a third party. This literature complements clinical textbooks and self-help manuals by explaining the human reaction to disease and disorder. Many of these works pertain to communicative disorders and to conditions in which communication is likely to be affected. A narrative sampling is included here (see sidebar), and a more complete annotated bibliography is available on the ASHA Web site: <http://www.asha.org/professionals/publications/kent.htm>

The Cost of Generalization

How should we understand illness and disability? Or perhaps the question is better phrased: How should we understand the lives of individuals who contend with illness or disability? Do we simply read our professional literature, and, as the need arises, recommend a good self-help manual to the clients of our clinical services? Is this enough?

Many textbooks and reference books have been written on the various afflictions to which flesh is heir. However, these writings generally document the specialist's understanding and are typically couched in the jargon of the medical and behavioral sciences. Because these sources frequently focus on the illness or disability, they tend to marginalize the person who actually has the medical condition. Missing from most of these technical books is a discussion of the human experience of illness—the initial reactions, the means of coping, the search for a diagnosis and effective treatment, the recovery process, and sometimes resignation to a changed way of life.

Self-help books and support manuals come closer to meeting the need for understanding the manifold dimensions



of illness and disability. But the majority of these emphasize the practical matters of day-to-day living and do not explore in its emotional depth the human predicament of being sick or disabled. Although these books and manuals are undeniably valuable, they often reinforce ideas of fixed stages of decline or recovery. The power of generalization comes at a cost, and part of that cost is that the individual is absorbed into a population, whether it be patients with Alzheimer's disease, children with autism, or the deaf. Much as we might struggle to instill a person-first terminology (e.g., saying "people with aphasia" rather than "aphasics"), the categories of illness and disability are the pervasive shorthand used by many specialists and laypersons alike: Mrs. Brown is a Hoehn & Yahr Stage 2 and Mr. Adams is a Stage 4 Alzheimer's. Even terminal illness has been cast into stages.

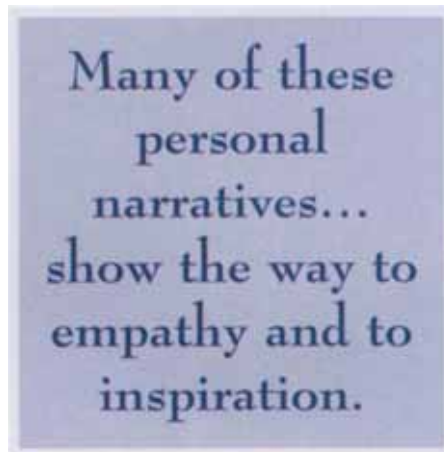
Although scientific accounts and support manuals can illuminate the personal facets of illness and disability to a degree, they cannot rival the power and conviction of the life narrative, whether written by those who are afflicted, by family members, or by specialists involved in their care. Many of these personal narratives teach something about the facts of illness or disability, but they go beyond clinical facts and syndrome delineation to give a central place to the *person* who has the illness or disability. They grapple with the emotional accompaniments of medical or other disadvantageous conditions—fear and despair, frustrations, excitement over steps of recovery, and satisfaction with successful compensations. They show the way to empathy and to inspiration. They can be valuable to individuals with illness or disability, to their family members and friends, and to the specialists who contribute to their care.

This literary genre is a complement to the professional and scientific books that weight our shelves. Is this parallel literary strand deserving of our notice, perhaps even to the point of including it in our curricula as a means of understanding our clinical mission? My own feeling is that it should be.

A Growing Literature Begets a Genre

As these writings have earned the notice of literary critics and scholars, they have

been gathered together under such rubrics as *pathography*, *illness narratives*, and *disability memoirs*. One regrettable feature of these genre names is that they all imply that the central focus is on disease or disorder. Granted that these conditions may have been the writer's immediate and sometimes primary motivation, they are not, after all, the ultimate and lasting virtue of the writing effort. What often emerges in the best of these accounts is not preoccupation with a bad turn of life, but rather lessons in endurance, resourcefulness, and overcoming. Books about cancer are not only about a malignancy;



they are also about survival. Books about aphasia are not only about loss of language; they are also about rediscovering communication perhaps in another form. Books about deafness are not just about a sensory disability; they are about the robustness and centrality of communication in human society.

A remarkable fact about these narratives is that they are so recent a literary accomplishment. As Anne Hunsaker Hawkins noted in *Reconstructing Illness: Studies in Pathology* (1993), "book-length personal accounts of illness are uncommon before 1950 and rarely found before 1900" (p. 3). But their presence is now undeniable, and they cover a wide spectrum of human travail. P.D. Kramer (1996) observed in *The New York Times*, in "The Anatomy of Melancholy," that "Bookstore shelves groan with memoirs of heart disease and asthma" (April 8, 1996, p. 27). The skeptic may ask if we are seeing too much of a bad thing.

Indeed, not everyone warmly embraces this genre. Anthony Daniels, writing for the *National Review* (October 1997, pp. 50–52), is surprised that so many people faced with illness would decide to write about their

experience. He identifies two reasons. First, unlike any other time in history, many people have never suffered serious illness. When illness does strike these previously fortunate folk, they must express their bewilderment, grievances, and outrage. Daniels rationalizes—and trivializes, in my opinion—the matter by drawing an analogy between the literature of illness and writings on travel to exotic lands: "Memoirs of illness are thus the modern equivalent of travel literature. Disease is a foreign country; they do things differently there" (p. 52). And so, breast cancer is considered in the same way as a trip to Mongolia.

Second, Daniels believes that, "Despite our longevity, unparalleled in history, we are in a state of existential funk" (p. 52). Having lost any vision that transcends our own mortality, he goes on to say, we pursue even the most marginal prolongation of our own existence. Victories over disease are reassuring in this narrow horizon of hopes and aspirations. Daniels, who is described in a footnote as a physician and traveler, seems to have little patience with books written by the ill. He has few positive words to spare and leaves the general impression that people who get sick should suffer in silence.

But the expressiveness of these resolute authors finds ready partnership with a new brand of medicine and allied health, one that departs from the traditional model in which the clinical specialist is the actor, and the patient is the passive (and often ignorant) recipient. In newer models, the patient participates with the specialist and both see validity and value in the patient's verbalized experience of the illness or disability. Patient testimony can be illuminating to the self and to others, even the book-wise specialist.

The curative model of medicine, for which cure is the chief or only goal, now has a rival that is attracting considerable attention. The rival is a palliative care model that is designed to offer active total care (see E. Fox, 1997, "Predominance of the Curative Model of Medical Care," *Journal of the American Medical Association*, 49, 50–52). Its objectives include relief of suffering, control of symptoms, and restoration of functional capacity.

Lessons for the Clinician

The very pattern of discourse between specialist and patient may come under examination, sometimes revealing that the

A Sampling of Memoirs

The annotated bibliography of memoirs available on ASHA's Web site (<http://www.asha.org/professionals/publications/kent.htm>) includes books in the following categories: General books on illness; Neurological Disorders (stroke, epilepsy, and brain injury); Aphasia; Deafness and Hearing Loss; Psychiatric, Dementing, and Developmental Disorders. Following are a few samples.

Bauby, Jean-Dominique. (1997). *The diving bell and the butterfly*. New York: Alfred A. Knopf. Bauby suffered a massive brainstem stroke that left him with locked-in syndrome (nearly completely paralyzed). He composed this book by using eye blinks to signal the letters one by one. His book is testimony to the powerful drive of communication.

Couser, G. T. (1997). *Recovering bodies: Illness, disability, and life writing*. Madison, WI: University of Wisconsin Press. Examines writing by and about people with illness or disability (HIV/AIDS, breast cancer, deafness, and paralysis). It also considers the genre of narratives by the ill and disabled.

Gardner, Howard. (1974). *The shattered mind*. New York: Alfred A. Knopf. (Reprinted in 1976 by Vintage Press, New York.) Gardner describes his purpose in writing this book: "to demonstrate that a host of critical issues in psychology can be illuminated by a thoughtful study of the behavior and testimony of brain damaged individuals." Among the disorders represented are aphasia, alexia, and memory impairment.

Hawkins, Anne Hunsaker. (1993). *Reconstructing illness: Studies in pathography*. West Lafayette, IN: Purdue University Press. This thoughtful book examines a literature the author calls "pathography."

Lane, Harlan. (1992). *The mask of benevolence: Disabling the deaf community*. New York: Alfred A. Knopf. Lane offers a historical review of attitudes toward deaf people in Europe and America. He also argues strongly against the use of cochlear implants in children.

Sacks, Oliver. (1991). *Seeing voices: A journey into the world of the deaf*. London: Pan Books. Sacks, a neurologist and prolific author, turns his writing talents to discovering deaf society. He reviews the education of the deaf in America, considers American Sign Language, and reviews the "revolution" at Gallaudet College. He argues passionately for ASL as the preferred language for the deaf.

Wulf, Helen Harlan. (1973) *Aphasia, my world alone*. Detroit, MI: Wayne State University Press. Wulf describes her recovery from aphasia, giving a vivid account of her frustrations and victories. Speech-language treatment figures prominently in her recovery, and the speech clinician is gratefully acknowledged.

pattern hinders the process of healing and restoration. According to G.T. Couser (1997), "Increasingly, people—inside as well as outside the medical establishment—are acknowledging that medical discourse, ostensibly and ideally the language of healing, may be at times counterproductive—that it may contribute to patients' suffering even as it purports to ease it" (p. 19). Furthermore, as several writers have noted (Couser; S.J. Reiser, *Medicine and the Reign of Technology*, 1978, Cambridge University Press; E. Shorter, *Bedside Manners: The Troubled History of Doctors and Patients*, 1985, Simon & Schuster), the growing reliance on technology in medicine has sometimes had the effect of reducing the physician's attention to patient testimony.

There are some important lessons to be learned about people who face sickness. Howard Gardner (1976) concluded that it is not possible to devise or freeze the mind at a single moment of time because "by its very nature, mind is a slow accumulation of increasingly differentiated representations of the self at different stages of development, affected and altered to some degree by each, but never erasing altogether the traces of itself at a more primitive stage of evolution" (p. 456). Illness narratives have the potential to depict the progression of the human mind in the face of obstacles.

Some of the books included in the annotated bibliography examine controversies and dissensions. For example, writings by Oliver Sacks (1991) and Harlan Lane (1992) argue for the legitimacy of signed language and against the use of technologies such as cochlear implants for the deaf. Interventions are often intrusive, and the intrusions may have negative consequences for some individuals. The rejection of cochlear implants is an example of the principle that innovations in biotechnology are not necessarily welcome to those who are expected to be their beneficiaries. The specialist armed with the bright promises of new technology should be forewarned that some patients may reject the sheer idea of such intervention. The rejection is rooted partly in a difficult history in which the destiny of the deaf was decided by the hearing.

Some books may be inspiration to aspiring clinicians and encouragement to practicing clinicians. Jean-Dominique Bauby,

whose brainstem stroke left him with locked-in syndrome, had this to say about his speech-language clinician: "The identity badge pinned to Sandrine's white tunic says, 'Speech Therapist,' but it should read 'Guardian Angel.' She is the one who set up the communication code without which I would be cut off from the world" (p. 39). Using this code, Bauby composed a short but stirring book, *The Diving Bell and the Butterfly* (1997). Another tribute to the speech-language clinician comes from Helen Harlan Wulf in her book, *Aphasia, My World Alone* (1973). For Wulf, speech treatment was "my life-line to sanity" (p. 50).

Conclusion

As the literature on illness and disability grows, it will be appraised by different parties for various reasons. Literary critics may question the lasting value of much of the writing. Even a partisan such as Anne Hunsaker Hawkins reached the conclusion, in *Reconstructing Illness: Studies in Pathography*, that "pathography is a genre that awaits its masterpiece" (p. 159). However, it should be noted that some of the books in the bibliography of the present paper have

received awards and critical acclaim. A few may emerge as masterpieces.

Some clinical specialists, uncomfortable with the unfavorable light in which their efforts are cast, might dismiss these writings as sour outpourings or entreaties for

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pity. But the most important appraisal will come from other people who become sick or disabled—or their caregivers. Maybe this audience is universal, for as Susan Sontag observed, "Everyone . . . holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place" (1978, *Illness as Metaphor*, Farrar, Straus, & Giroux, p. 3). ①

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